

# COMMUNICATING TOGETHER

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A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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# EDITORIAL

NOLA MILLIN



*We were delighted when Nola Millin agreed to guest edit this issue of **Communicating Together** that focusses on AAC users speaking out about "Who we are." We are deeply moved by the very powerful, sometimes disturbing, but always eloquent submissions sent to Nola from AAC users. We thank Nola for this editorial. Her understanding of the issues far surpasses ours. In our December, 1993 editorial we commented about the help needed from AAC users at all levels of discussion. With Nola Millin's editorial for this issue, we rest our case!*

*Shirley McNaughton and Peter Lindsay*

*P.S. Our "help" to Nola which she mentions in her introductory remarks was procedural. The editorial decisions were hers!*

This has been an exciting issue to watch develop. There has been a mix of my emotions as things have gotten put together. The intention was to have the March issue written totally by AAC users. Unfortunately, I wasn't able to achieve that goal since I received a limited response from AAC users which was frustrating. However, I'm delighted with the users who did write articles. I'm also grateful to the other associate editors, who faithfully wrote their usual columns and tolerated my many faxes that asked questions about their material. A very big thank-you goes to Peter and Shirley,

especially Shirley, for allowing me to undertake the responsibility of this issue. Without her help and support, this issue would not have been put together. What you now have in your hands is the result of various faxes, Blissnet messages (an electronic mail system), and phone calls between Shirley and myself. I feel it has been worth while.

The theme I asked the AAC users to write about was, "*Who am I? How do I feel about myself?*" I realize that in many ways this question is complex. A person's entire being makes up the answer, so I know writing an article on this topic would be challenging. Editing the material I have received has made me reflect on what my response would have been if I had written on the topic. As an AAC user, I experience a lot of obstacles along the road of life but I perceive them as challenges not as barriers. I feel good about myself and I don't see myself as being handicapped by my disability. Yes, there are times when it is inconvenient and down right frustrating to deal with the problems of being a person with a disability. But, like the others, I have learned to cope with life. It has been interesting to see how other AAC users cope with the ups and downs in their lives.

As AAC users, we have the additional task of making ourselves understood. For example, when I'm out alone somewhere and I'm facing a barrier such as a step or two that I can't manage in my wheelchair, not only are those steps a challenge but asking if there is an elevator is another barrier. Situations like these are common to an AAC user. Fortunately most of us use AAC devices that allow us to function relatively easily in society. It is those challenges that help make up who we are. One person might see a situation

in a positive way while others see it negatively. In my opinion, how we cope with the challenges of life as AAC users, help to answer the question of "*How do I see myself?*"

I think all of the material written by AAC users addresses the issue of "Who am I?" "How do I see myself?" A lot of the writers share some of the frustrations of being an AAC user and/or having a disability. In other articles people share how their AAC device has opened many doors and has allowed them to achieve some of their goals. It is my hope, that if you are a professional working in the field of AAC or if you are a parent of an AAC user, you will read these articles very carefully. They offer insights on how parents and professionals can either help or in some instances hinder the AAC user. I know the material will be thought provoking and even inspirational.

I'm pleased to have the article by Rev. Lee Mehrlich as the feature for this issue. First of all, I would like to extend our sincere sympathy to Lee on his mother's death. I greatly admire Lee's willingness to write his article under the circumstances. Lee's article sparked the idea of doing a tribute to Lee's mother, Myra Mehrlich. As you will read, Lee has great love and respect for her. She has helped him in many ways. He describes how she supported his communication. Through her determination through the years, he obtained the graphic system and device that worked for him. With his AAC system and much "people help", Lee was able to achieve his goal of becoming a Lay Minister. Lee's article has reminded me of my own mother and the major role she played in advocating for my needs. Lee is a great example to all of us. I'm sure



his mother would feel very proud and honoured by the article he has written.

There are two articles in the *Teaching & Learning* section. This section can be tricky to write since we try to focus our material around an educational aspect. I know because I'm partially responsible for the column. I decided to place an article by Mary Ann Merchan and one by Alan McGregor in it. There are some similarities between these two articles in that they both deal with a lot of issues that affect the lives of AAC users. The frustration with inadequate equipment, the challenge of getting education, and the reality of unemployment exist for many of us. These are topics that have surfaced in other issues of **Communicating Together**. Although, they have been discussed before, it never hurts to bring them up again. These are issues that can affect the self-worth of any individual, not just those who use AAC devices. Unfortunately, for the AAC user these issues become even greater since they are added to our other difficulties. Both Mary Ann and Alan talk about how they have overcome their difficulties and have found a sense of self-worth.

As usual Kari Harrington has written the *Living* section. In addition to Kari's poem, we have included an article by Dr. Annalu Waller. First of all, I'm sad to say that this is Kari's last contribution (for the time being) but I'm grateful that she decided to wait until *after* this issue to resign. Kari's poems and Annalu's article offer a tremendous insight into what I think many people with disabilities feel. I know I can relate to Kari's first poem quite well since I don't feel disabled. Obviously, I'm aware of my disability; dependence on my wheelchair and AAC devices; and my need for attendant care — but yet inside of me I feel "normal." Kari's second poem and Annalu's article talk about experiences that are unique to them. Although, we might not be able to relate to their experiences, I think we

can all relate to changes that are occurring to our bodies as we increase in years. It's an uncertainty we all face sooner or later. For those of us with disabilities the changes can be even more limiting which is scary and frustrating. Thanks, Kari and Annalu, for sharing such personal experiences.

Paul's article challenges the disabled population to live their lives to the fullest. In his profound style of writing, Paul addresses the theme of "Who am I?" head on. He admits that there are difficulties in life but says it is up to each one of us to choose how we will cope with our trials. Although he doesn't talk about specific topics, he does say that to make the most out of life, a person has to take risks. I agree with Paul. Risks allow us to experience and discover who we are in life. I admire Paul's ability to write such an article and offer such inspirational advice.

The rest of the articles are written by "normal" able-bodied people. (I question the word "normal.") First there is a poem by Carol Lynn Katsios. As a care-giver, Carol Lynn's poem looks at the unique relationship between an individual and their care-giver(s). I know in my life, there is a fine line between what a caregiver is and what a friend is because all of my close friends know how to assist me with my needs. Obviously, I have friends who know how to care for my needs more than others. The relationship with a caregiver is quite personal. Even the attendants who work in the building where I live are my friends. Carol Lynn's poem puts it well: We become entangled in each other's life. It's a relationship an AAC user knows very well.

In some way, Rob's *Consuming Technology* section and *Contexts* by Geb are parallel to each other. Rob's article is the second part of the article that appeared in the December, 1993 issue. Rob continues talking about the

need for more involvement by AAC users in the production of AAC devices. I know some AAC users feel strongly about this topic as well. We are the ones who use these devices so, obviously, we are able to give the manufacturers constructive feedback which would allow them to make more functional devices. This idea comes through again in Geb's article. He says that in many ways, society defines what "disabled" is. Like Rob, Geb feels people with disabilities should be seen as contributors and be able to work with manufacturer/researchers and others in the rehabilitation field. For those of you who have read my previous articles, you will know that I agree with both Rob and Geb. It is interesting to remember that back in high school I wrote a paper entitled "How Society Handicaps the Handicapped". Remarkably, and unfortunately my paper still holds true today.

The *Perspective* talks about a programme that is offered by Temple University that *instructs* AAC users how to be self-advocates. The programme gives intense training on how to use an AAC device. I read the information with mixed feelings. From the material I received, the programme sounds good and the participants seem to benefit from it. Yet it leaves me wondering what has gone wrong in "a system" that requires adults to be *trained* to self advocate. I also have questions about "able-bodied" people instructing AAC users how to be self advocates. I feel the best teacher is one with whom the students can identify. I should know! I've lived it!

I hope you enjoy hearing from the AAC users and the others. I have enjoyed the challenge of putting the issue together for you!

Nola Millin

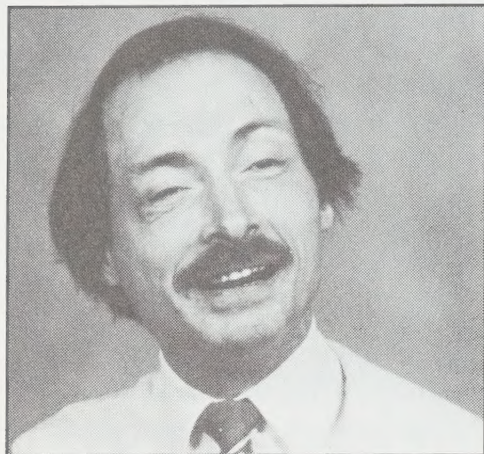
## Next issue:

Our theme for the June issue will be decided at our upcoming planning weekend of the **Communicating Together** associate editors. Please send your suggestions.



# COMMUNICATING THROUGH GRIEF...AND LOVE

REV. EDWIN LEE MEHRICH



*Rev. Edwin Lee Mehrlich, a resident client of St. Vincent New Hope, Inc. in Indianapolis, Indiana, is a certified Lay Minister of the Disciples of Christ Church. His ministry is classified to those who use augmentative speech. Lee, challenged with cerebral palsy, is a writer of articles in Blissymbols. He is the co-chairperson of the new Religious Blissymbolics Committee of Blissymbolics Communication International and an active minister in Zionsville Christian Church. He was assisted in doing this article by Chaplain Catherine Bielski, coordinator, Pastoral Care, St. Vincent New Hope, Inc. This article was submitted in Blissymbols. An excerpt is presented in its original form in the adjacent box. We thank Lee for sharing his thoughts with us.*

It is difficult to know that someone you love is very sick. What seems to be helpful is to hope he or she will get well and to remember that person for who they are, for their strengths, their smiles, and the many ways that they urge us on.

My mother was again in the hospital. The thought of not having her made me afraid of the future. I thought that my life would be empty, as if there would be a big hole in all

I know. Although the doctors thought that she would be coming home in a few days, my worst fear came true. I was told that Mom had died. We were all filled with great sadness!

I have heard that men do not cry. This is not true for me. The thought of Mom not being there for me and the rest of the family was very hard. My pain is still real and so are my tears. They allow me to let out pressure that is bottled up inside me. I feel that my tears show how much I love my mother. I shall not stop them.

Mother's death is a very big sadness for us. There is so much in her that we do not want to let go of her. All my life she has been an advocate for me. Because I could not speak, she was my mouth. To help me communicate, she helped make my first Blissymbolics communication book with the help of students at the University of Florida, 23 years ago. Mom was on the

Board of the Easter Seals in Florida and advocated for me and others with cerebral palsy. When we moved to Indianapolis in 1984, Mom, and Donna Potter, Director of Speech Therapy at St. Vincent New Hope, Inc. joined with my church, Zionsville Christian Church, to get money to buy my first augmentative speech communication device — a Touch Talker™. With the help of Shirley McNaughton from Canada, I was able then to help program the Touch Talker™ in Blissymbolics. Being able to communicate has brought happy times into my life and my mother's life.

I recall my mother's eyes when she heard that I had passed my examinations to become a Lay Minister for my Church. She cried and looked so happy. I was able to communicate with four state-wide ministers, who came to test me. I had to answer all their questions along with handing in my written work. I used Blissymbolics in my

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Because I was not able to speak, she was my mouth.

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book and my Touch Talker™ to help me communicate with them. I will never forget Mom's tears of joy. During all of these changes in my life, Mom was there for me. She is still with me. Now, both as her son and as a Lay Minister for the Disciple's of Christ Church, I wish to be there for her and Dad and for my family.

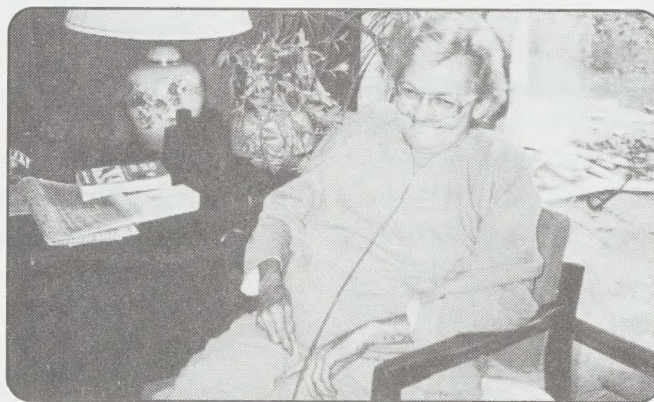
I am my mother's oldest son and I wanted an active part in her funeral. It would be easy for everyone to direct mom's funeral without my input, leaving me on the side of the room alone. And it could have been easy for others to look over the head of someone, like me, in a wheelchair, and while talking to another person, ignore me. Because of my Blissymbolics and Touch Talker™, I was able to have an active part in Mom's funeral. I met and communicated with people who came to support us in love. I felt good and useful because I could "talk" with them. My experience showed me that being able to communicate helped me to feel independent and more in control at this very hard time.

For me, Blissymbolics is "God-Language". It gives power to me for it helps me to communicate clearly when I can use symbols that others can understand too. Just as in this funeral, my relationship with others was helped by my communication devices, my ability to succeed in the future will be made possible by these and other friends whose help and love give me strength. My Blissymbolics book and Touch Talker™ will continue to remind me of the woman whose strength still moves me forward. Mom urges me on from Heaven. I hope that I always communicate with her kind of love and care for others.

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## Tribute

*Myra Mehrlich possessed the strength and determination and the belief and pride in her son with cerebral palsy, that we would wish for all parents of AAC users. In this, our feature article, Lee describes some of the many things his mother has done for him over the years and his deep sense of loss at her death. We wish to add our tribute to Lee's mother by dedicating this issue of **Communicating Together** to her memory. Given our theme of "Who am I? How do I see myself as an AAC user?", we can think of no better example of the help parents can provide than that exemplified by Myra Mehrlich.*



*Throughout the years, she was sensitive and caring, she fought to extend Lee's communication abilities, she took an active role in each living and learning opportunity available to Lee. Her optimism and willingness to try new approaches was an inspiration to all who knew her. Although her own health was failing steadily during the past several years, her interest in all her family and her special support for Lee were always present. We know Myra Mehrlich will be remembered with pride by her husband and sons and their families. We hope her inner strength will remain with them all, and continue playing the special role it has always done for Lee.*



## Once Positive, Now Discouraged

KARI HARRINGTON



When we received Kari's contribution for this issue, we were concerned! The Kari we are all accustomed to interacting with can always see the positive side and is ever optimistic about the outcome of situations. Her latest poem alerts us to the impact her physical condition is having upon her emotions and perspective. In response to Kari's hope that she and others will come to better understand what is going on in her mind, we asked Annalu Waller if she would be willing to share the difficulties and feelings she is currently experiencing, which like Kari's, have arisen from reduced physical capabilities.

We know there are many persons, both those who have cerebral palsy and those who do not, who face similar depression. We hope Kari's and Annalu's writing can help all those struggling with physical limitations to realize they are not alone. We feel privileged to be allowed to share Kari's poetry about her "other world" and Annalu's description of her inner roller coaster of emotions.

We thank both Kari and Annalu for sending their thoughts to us for publication. We hope they will find the strength to continue their physical battles. The real Kari and Annalu must continue to grow!

When I was younger, I didn't think of myself as being disabled. I was happy most of the time and developed good, positive feelings about myself and all the things I was able to learn to do. I expressed this in my poem

### Look at Me

*When some people look at me,  
They see a girl in a wheelchair.  
I can tell what they are saying.  
They are saying, "That girl can't walk."*

*Look at me, look inside of me.  
I'm moving in a special way.  
Without this special chair,  
I wouldn't be moving at all.  
I can walk with a person behind me.  
Inside of me, I'm walking.*

*When people see one hand working,  
They only see a very few of the things  
I can do.  
They're saying,  
"She can't do much with one hand."*

*Look at me, look inside of me.  
I always try something new.  
I do things in my own special way.  
You'd be surprised to see what I can do.  
I can do a lot of things  
That you can't do.  
Inside of me, I can do everything.*

*When people hear me talk,  
They don't understand a word.  
I can tell they are saying,  
"That girl cannot be understood."*

*Look at me, look inside of me.  
I can talk.  
You just have to take time.  
I can talk in so many ways.  
Whichever way I use to talk to you  
It will be fun.  
Inside of me, I can go on talking forever.*

*Most of all, I look at myself  
As the way God made me.  
I see that I am lucky  
That I'm this special person.  
Inside of me, I believe in myself.*

Now I am in my 30th year and I *do* feel disabled. Since my surgery three years ago, I have become frustrated by many health problems that never seem to get resolved. The extra medications I have to take make me feel unwell and at times I get very discouraged. I began to have this experience of going into another world. You may think it is a way for me to get away from my problems but it isn't. It's scary! It's hard to explain what exactly happens. I am hoping my poem and the picture I am now painting about it, will help me and other people understand what is going on in my mind.

### What's This Other World?

*Right now I'm in the real world  
With people around me,  
Sounds that I can hear  
And living things and objects.  
I can deal with all of these.*

*Wait a minute.  
My mind is going through a door.  
The place is all grey and black  
And I can no longer deal  
with the real world  
What's this other world?*

*I look around.  
There's not a single person, sound  
or object.  
A black forest is all I can see,  
And I turned black too.  
What's this other world?*

*Lonely and scared,  
I run back to get out,  
But it seems I'm locked in.  
I'm crying and asking,  
"Get me out of here."  
What's this other world?*

*At last I'm out  
Into the real world  
with people, sounds and objects.  
Still I have to know.  
What's that other world?*



# My Inner Roller Coaster

ANNALU WALLER

## Some Background

Who would have ever thought that a week using a new computer would threaten my whole person both physically and emotionally. Well, it did. After a week of using the small trackball on the Apple PowerBook, I developed an excruciating pain in my right wrist. I was referred for ultrasound two months later having had no success with anti-inflammatory tablets or a cortisone injection. The usual cure for repetitive strain injury (tendonitis of the right thumb extensor tendon, in my case) is rest. Well, those of you with athetoid CP can imagine how impossible it is to keep my hand relaxed. We even tried splinting it, which only made it worse. I was not supposed to use it at all — impossible as I live alone. The physiotherapist gave up a month later and I was then referred to the orthopedic surgeon who eventually resorted to surgery seven months after the original injury. My father came to look after me after the operation in November, as I wasn't allowed to use my hand at all, rendering me totally dependent as my left hand is my "bad" hand. The surgery usually has a 100% success rate but no one predicted the effects of my cerebral palsy on the healing process. My tone was so increased that the tendon was constantly in spasm. I was off work for two months and knew that nobody knew what they were doing. Slowly but surely I felt myself losing all sense of control and began imagining that I would never get back to work. I live for my work and it ensures my independence. Suddenly I wasn't even allowed to drive as it increased my thumb movement. Goodbye freedom.

## Emotional Effects.

By Christmas I was down, down, down and it was a very bad time for me. I was in tears most of the time, much to my horror. All I wanted to do was to stay in bed and make the world go away. Every time somebody asked me what the matter was, I burst into tears. In fact, I kept on thinking about the time just after the operation on my wrist when I had a reaction to morphine, fainted and was later told that I had stopped breathing. All I remember was being in a warm, very peaceful cotton woolly place and resenting being called back. It was scary when I realized where I must have been. Everyone looked so worried when I opened my eyes. But how peaceful that place was.

Anyway, back to Christmas. Every time anybody spoke to me I burst into hysterical tears (typically C.P.). I felt as if I was in a ball physically, and wished someone would stretch me out. Dad, Sharon (my sister) and the friends we were staying with were so worried that I was eventually persuaded to start a course of anti-depressants. I was determined not to take anything as I didn't want to be "drugged". Yuch! I gave in. But they made my body twitch like crazy and I could not stand up one evening. I am now on different ones which have helped me get back to normal! The worst part was feeling that you're split in two.

My mind keeps on telling me to get real and knows things have to improve. My emotions, on the other hand, just see a black hole. In my case, I feel no one really knows what I am going through and it is as if the medics won't admit they are at a loss. The irony is that I nearly jumped with joy when the hand physiotherapist was explaining my problems to another physiotherapist and using technical terms which

basically repeated my worries. The surgeon seemed to ignore my concerns, making me feel like a fraud.

But back to how I feel. What made me even worse was people telling me to snap out of it. One of the good things though is that I am now able to talk without crying. I was able to go up to Inverness recently and could talk to my surrogate mother without howling hysterically. Another awful fact is that everybody is so concerned, which often makes me feel worse.

One of the most important facts is that it has made me far more aware of my limitations and has made me start questioning a lot of the baggage I now realize I am carrying. I believe that when we (i.e. people with physical problems) have to face too much at one time (or over a long time), we find it hard to cope. I have had physical hassles and operations before. But all the implications this time, plus my car breaking down for four weeks — all takes its toll.

So... Well, I have eventually found a private NDT physiotherapist to "straighten" me out. I have got the O.T. to provide me with some more gadgets. I am about to start riding again. Well, all that was before I developed a terribly sore crick in my neck — probably from the treatment the physiotherapist tried. But I still went riding. The hospital's hand physio-therapist has now admitted defeat, and the muscle-relaxants to try and reduce the spasticity in my wrist have increased my athetosis making walking and typing really difficult. I wish that for once the medics would know something about CP!!!! They try, but it is always up to me to push and make suggestions. So back to the drawing board.

One of the best things friends said to me when I was really down was



not to make any long term decisions while I felt like that. They also stressed that I would feel better again. And, although I still feel shaky, I am beginning to see the light again and am actually looking forward to the future, whereas three months ago I wanted to disappear! My wrist still hurts, and my general muscle tone is up the creek, and I suspect this is the new me, but that is just the "outside me"! The real me can still grow!

It has been helpful for me to know that other people have experienced the same sense of loss and despair that I have been through. I have been lucky in having a knowledgeable circle of good friends who have understood that my depression is similar to that experienced by people without disabilities. Much of my improvement has come about by being able to talk about how I feel and what I was going through. It worries me that so many people might not have the opportunity to "talk" to someone slightly removed from family and/or carers and to have someone who believes in them enough just to stand back and wait for the person to emerge from the darkness. Having read Kari's poem, I can feel for her, even though I can never know exactly what she's going through. All I can say is it does get better eventually.

February 18th. The latest news is that the hand physiotherapist wrote a letter to the surgeon saying she couldn't do anything for me. The surgeon and four colleagues saw me on Monday and have said they have exhausted all options and knowledge and have referred me to the pain clinic (waiting list three months). And my hand is getting worse by the day! Oh well, my mom has set up umpteen appointments when I am in Cape Town in March!!!!

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*Over the years, Carol Lynn Katsios has contributed many articles to **Communicating Together**. We are very pleased to include this poem in our Living section. It was written to a friend, who is an AAC user, when Carol Lynn decided to postpone her move away from Ontario. Carol Lynn has interacted in many ways with adults who have physical disabilities, including supervising a support service project and assisting presenters using AAC in a community awareness service. She is currently involved in a literacy program directed to adults who have speech and physical impairments.*

## LIQUID BLUE

I will walk with you  
a while longer.  
We've been swimming  
in each other's lifestreams  
for so long  
that our rhythms are well known  
to each other.  
We have grown close,  
and we find comfort  
in each other's presence.

We have shared  
the mist,  
the thunder,  
and the quiet times in the moonlight.  
When I loved the whales,  
you loved them, too,  
and brought me songs from the sea.

And I loved you  
for the treasures of silent laughter  
that you offered me freely,  
like pearls on a silver cloud.

Perhaps  
if we journey together a while longer,  
we may discover new seas  
with our names written in their depths  
in liquid blue.

carol lynn katsios



## Supporting the Empowerment of AAC Users — II

ROBERT HAAF



In the last issue, I began a discussion of technology development and provision from the viewpoint that AAC users, families of users and clinicians are all “consumers” of technology at different levels, and that *all* parties are entitled to give and receive direct feedback in the process of technology development in AAC. In this issue I would like to continue this discussion, first by presenting the views of an individual who is involved in the development of new communication technology from the “ground up”. Fraser Shein’s comments help us define the process of collaboration in the development of communication technology, and helps to pinpoint some of the barriers to such collaboration that must be accepted and overcome. I’ve also invited the comments of one of our associate editors, Paul Marshall, who plays an important consultative role in the Technology Consortium described below. Paul’s comments were directed at more general concerns, and they led me into some closing thoughts for this ‘theme’ and to reflections on the past year of *Consuming Technology*.

Fraser Shein is the coordinator of the Communication Team of the Ontario Research Technology

Consortium. Based in Toronto, Canada, the team works to facilitate the development of communication devices that will best meet the needs of users. Presently, a major focus is the design of a comprehensive, computer-based portable communication system incorporating modules to support face-to-face and written communication, telecommunications, environmental control and more ‘specialized’ communication functions such as making spoken presentations. This system is based on existing software (such as the Windows Visual Keyboard, WiViK) for adapted computer access, and the various modules are being developed around these interfaces. The system is being designed to include many unique features, such as the expression of emotion through synthesized output, the ability to recall stories, and even to modify recalled stories and phrases to provide some degree of natural variation in message form. The Consortium distributes communication products like WiViK through Prentke-Romich Co.

Fraser responded to my questions regarding user involvement by first expanding upon my definition of ‘consumer’ to include families, all communication partners, the general public and industry. All of these viewpoints need to be considered, and a balance must be found among them in the design of new devices. As expected, a primary source of information is clinician report: Fraser indicated that since clinicians are involved with device assessment, training and customization, they often have a broad view of the strengths and weaknesses of a specific device. Individual users typically experience a smaller range of device characteristics (and problems). Consortium developers also rely heavily on information from

device distributors such as PRC, who can provide valuable “front-line” information gathered from professionals and users. Developers gather information directly from users through face-to-face interviews and questionnaires exploring desirable features of new devices. Since accessibility and travel can be difficult, going to users’ homes to conduct interviews is becoming more practical than the time involved “getting users to researchers.”

In addition to providing such information, users are directly involved in research projects to develop new technology, and in the Beta Testing process for new devices. Two bodies providing input into the Consortium are the Consumer’s Advisory Board and the Consumer-Researcher Collaboration Committee, where users of AAC devices (such as **Communicating Together**’s associate editor Paul Marshall) have consistent access to the developers to present and discuss ideas. Fraser stated that the individual AAC user should also provide information directly to clinicians, and feed back to developers through the distribution channels (e.g., companies like PRC). These distributors need to be aware of consumer concerns. In some cases, the concerns relate to the distribution system for devices and not the devices themselves.

In discussing advocacy, Fraser offers the view that users should strive to be *partners* with developers instead of advocates: Developers are “already sold” on the technology and on supporting the needs of the disabled. What developers need most from users are specific ideas as to how to provide a better product. Fraser suggested that it is important for developers to have different types of information from different



stakeholders. Clinicians and other professionals can provide general ideas about technology. The end users can offer more specific information about device operation. Researchers and developers can act more quickly and easily on this type of information.

If AAC users and other consumers are to be partners with developers, Fraser feels that there needs to be a clear understanding of the process of developing and marketing technology. The role of each participant in the decision-making process must be well defined at every stage of development. He states that all participants should recognize that the goal of development is to garner the minimum amount of information necessary to get the job done efficiently. Recognition of this goal helps to maximize the effectiveness of any input provided. He feels that developers need a more systematic way of maximizing consumer input, and cited as an example a "heuristic evaluation" of WiViK that was used to identify most of the initial problems in a very short time. Also, users need to be more aware of the time it takes to transform ideas and suggestions into products: Fraser indicated that it is typically at least a year before new products are available.

When discussing potential barriers to establishing a direct user-developer partnership, Fraser felt that accessibility was a major problem. If it is too difficult or time-consuming for either party to travel, users need access to developers through other well-established and accessible channels of communication. To ensure that their input is heard, users need to have an effective medium to present their ideas, perhaps requiring the use of less time-dependent channels such as telecommunications, or the means to prepare ideas and presentations beforehand.

As I was writing the article for the last issue, it was my feeling that clinicians continue to have better access than AAC users to technology developers and distributors, and that both users and developers are too often forced to rely on clinicians to provide critical information. Based on my discussions with Barry Romich (in last issue) and Fraser Shein, I now feel that this trend seems to be reversing itself (at least in some respects). This should be encouraging to everyone involved. However, this topic initially arose out of a consideration of 'advocacy and empowerment', and the comments I received have confirmed my belief that these terms have a unique meaning when the provision and use of technology is considered. This discussion has raised larger issues about what constitutes the "empowerment" of the individual and the family in making decisions about one's communication.

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### **The role of each participant in the decision-making process must be well defined at every stage of development.**

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I agree with Fraser's comment that when determining how best to develop new technologies, advocacy is *not* ultimately as productive as partnership and cooperation. There is a parallel here, though, within the client - clinician relationship. I have met individuals who have felt that "advocacy" means doing whatever one can to ensure that a disabled individual receive a particular piece of technology, in the belief that technology *in itself* can make a difference.

Often in response to a brief exposure to one attractive piece of equipment, such efforts are directed towards the technology as an end, and not the real-life 'gap' that the technology is supposed to help fill. This kind of 'advocacy' disregards the fact that an individual must carefully examine his or her own needs before deciding if technology will be of benefit to their lives. Often fact that technology is most often useless without a vast amount of ongoing training and support from a number of people is not often taken into account. Actually, I think Paul Marshall states the case much more eloquently:

*We have to be careful when we are involved in the design of any new technology. It is so easy for us to get caught up with glory in the technology that we forget these are tools to improve quality of a life and not solve everything. There is a risk of becoming so involved with high tech that we can forget about the 'person' we are trying to help.*

*In designing any new equipment, we should question: a) will this improve the quality of life without taking away some self-worth (from) the individual? b) Are we giving this technology at the right time in an individual's life? c) Have they mastered the skills to their fullest ability and are they ready?*

*Now since I got myself out on a branch, I had better do some explaining before the saw takes its last stroke. We must let the individual develop to their full potential. If this means not giving them up-to-date technology then we have a responsibility to hold back and wait. If the individual is in need and we have the technology to meet that need then by all means give that technology."*

If advocacy is to be effective it *must* be focused on the needs of the individual. There can be no other agenda. If there is, the action being taken is not "advocacy" in any true



sense. We need to advocate not for a device, or even access to devices, but rather for access to a *process* for defining mutually-determined communication needs. We must then consider all of the options that will together provide the best communication system for an individual. The support and dedication that is necessary from all people involved must also be determined before a device is even considered. This is where clinicians play a role in educating the clients and families in the entire process, and not just in the range of specific devices available to consume.

If AAC users and families are to become empowered and independent in making decisions regarding technology, then choosing among possible devices is *not* the primary question: Whether or not an individual truly needs technology to communicate should be the first decision, and that is always the starting point in working with my clients. Quoting again from Paul:

*Today when we talk about a Bliss Board we are talking low technology, but a very vital part in many AAC users lives. It almost seems to be taboo to think a person may want to stay with a low tech way of communicating. After all, why stay with something that doesn't have speech output, the ability to store messages, and doesn't have the up-to-date capability? Wow! Something is wrong if I don't make use of and I don't worship the high tech age.*

In my brief experience, I have seen many highly successful communicators who rarely (or never) rely on technology to communicate. The most obvious example is another of **Communicating Together's** associate editors who grew up and attended and graduated from university relying primarily on a word board and electric typewriter. When presented with all of the information

and options, some individuals decide that the time commitment for learning and using technology is just not worth the effort when the actual gains in communication competence are minimal. Technology is not for everyone at any point, and only a consideration of the strengths and needs of the individual can determine what may be right for a person at that time. I know from personal experience how easy it is to become excited about advancements in technology. This is a positive trait for those involved in AAC to have, as long as it does not begin to interfere with one's ability to step back and ask if the exciting new development will really be of any benefit to the person in front of you.

Movement away from a clinician-dominated and medically oriented model of AAC service delivery, and towards a family and client-centered model is a trend much discussed of late. In the move towards the empowerment of the client, clinicians are sometimes being viewed as very proprietary in regard to their knowledge of technology, and are accused of jealously 'guarding the gate' to technology against entry by many individuals. If AAC professionals are viewed as simply 'providers of devices' and *not* also the information, guidance and support necessary for communication success, insistence on a process that involves clinical input from the outset may easily be viewed as protection of our 'turf'. In truth, competent clinicians work to emphasize the need for education, team-based decision-making and using 'real-world' outcomes to decide if technology is of benefit. When this approach is well applied, disabled individuals are *not* prevented from having technology, and just may have a better chance of success when technology is introduced. We should pay careful attention to Paul's caution about letting technology become central in

the communication process. If the perceived *need for technology* becomes central in the mind of a client, his/her family or other individuals, the *need for communication* can be lost.

It has now been almost a year since I began writing this column for **Communicating Together**, and I feel that this represents a milestone of sorts that is worthy of a brief comment. During the past year I have always tried to be conscious of how easily a column devoted to technology can come to focus too strongly on those aspects of the field that are 'easy' and attractive. As I stated in my first article, discussing the limitations of technology, and the role of technology in the lives of individuals is much more compelling, and it seems to fit easily within the humanistic forum that is **Communicating Together**. I sincerely hope that the directions I have taken in this column have provided **Communicating Together** readers with viewpoints and issues that are relevant and worth pursuing. Submission deadlines aside, I have enjoyed the experience to date, and have been enriched personally and professionally by the individuals who have provided material for the column. I look forward to the coming year.

*My thanks to Fraser Shein and Paul Marshall for their willingness to contribute to this issue. I also want to take this chance to extend my appreciation to Shirley and Peter for their continuing support and encouragement of my efforts in this column.*

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#### Have You Moved?

Please remember to let us know your new address. If possible send an address label from a  $\pi$ past issue to: Communicating Together  
P.O. Box 986, Thornhill,  
Ontario, Canada L3T 4A5



## Who Am I? How Do I Feel about Myself?

NOLA MILLIN

*Below are two responses from AAC users to the challenge to write about **Who am I? ..and How do I feel about myself?** The first one is from Mary Ann Merchen. Through our recent correspondence I can tell she is a very busy woman. I'm glad she was able to find time to write an article for us. We welcome her insight.*

## My Life: Not Wonderful But Certainly Not Awful

MARY ANN MERCHEN

I was born thirty-seven years ago in Danville, Illinois. While my parents have had a home in Danville all my life, I had to attend a residential school in Chicago which is 125 miles from my hometown. In the sixties, mainstreaming was not even a term.

When I was six, this school had a waiting list, which was why I was not able to go to the school until I was eight. Within a few months after beginning school, I was using a headpointer to type on an electric typewriter. Since I have cerebral palsy that causes me to have only fair control over my muscles in my entire body and a moderate speech limitation, I loved using a headpointer to type. The fact that I was slow didn't matter. I was just thrilled that I could write like anyone else.

At the age of eleven or twelve, I began using the Cyber-Type which was an adapted IBM typewriter with a keyboard that had only seven fairly

large round keys. Although I had to press two of these keys to get a character, using the Cyber-Type was better than using an electric typewriter because I did not use my headpointer. I used my left hand to press the keys.

I used the Cyber-Type for only a little while because the inventor of it changed something which gave the typist feedback. While the change was small, it made using this special typewriter very hard for me. As a result, I had to go back to using my headpointer. For some reason, though, it slipped off my head quite a bit. Because of this fact, I relied more and more on people to be writers for doing my homework and letters.

Since I have always preferred to do my own writing, I was happy when I was asked to try the Auto-Com when I was sixteen. I used three models of this communication aid, which looked like a Unicorn Expanded Keyboard but did not need to be connected to a computer. My last two models had narrow screens as well as printouts. In addition, they could store words, phrases, and sentences.

The Auto-Com opened a whole new world for me because writing was so much easier with it than it ever had been. This fact was even true with the first model which had to be connected to a T.V., which could be any size, making this model only semi-portable. Of course, this arrangement was not ideal, but it allowed me to do almost all my school work and letter-writing independently. As well, it permitted me to talk with more people than I ever was able to converse with before. Being able to communicate easily made me feel

like a whole person, who had something to offer other people.

Since I felt this way, I now wanted to go to college and have a job. I was very naive when I was in college and took courses which were supposed to allow me to be a mass media consultant. The reason I mention that I was naive is that I decided to go into this area because an assistant journalism professor and my Division of Rehabilitation Services counsellor encouraged me to be a mass media consultant, knowing that strangers can understand only a little of my own speech. When I was deciding what kind of career I wanted, speech synthesizers were not on the market.

By the time I had realized that being a mass media consultant would be almost impossible for me, I was only a few courses away from completing all my requirements. Therefore, I decided I would send my resumes and a cover letter to companies that make communication aids, saying I would like to work in the Advertising, Marketing, or Research Departments. With my knowledge that I had received in college, I felt confident that I could help design ad campaigns, marketing strategies, and/or written questionnaires. In addition, I actually wanted to work for a company that makes communication aids and/or systems. That is why I followed the advice of an assistant journalism professor and my Division of Rehabilitation Services counsellor and received a degree in Mass Communication.

Since I had experience with communication aids and knowledge about advertising, and marketing, I thought I would get a job quickly. I did not, however, and still do not have a job, after graduating from college in 1983. For several years, I kept my



apartment in the town where I went to college and concentrated on writing articles mainly about different aspects pertaining to people who have speech limitations. While I had quite a few articles appear in *Communication Outlook*, as well as in, at least, two other magazines, I was paid for only one. It appeared in *Accent on Living*.

Thinking that if I had more education I would be paid for more writing, I began to work on earning a Master's degree in Psychology in 1988 at another university. I, however, did not have enough motivation to finish work for the MA. The main reason I did not have the motivation was that I could

not find another communication aid to replace my last Auto-Com which stopped working in 1985. Prentke Romich stopped making Auto-Coms at this time too.

Finding information about communication aids can be hard. As a result, I have started *Voices*, a newsletter for people who have special needs, particularly who have a problem talking. I try to get an issue out every other month. While the newsletter isn't as professional as I would like it to be, I hope it offers some useful information in an easy-to-read style. A year subscription for people who have special needs but are not working is \$6;

for persons who are working and who may or may not have any physical problems the fee is \$10.

Although I don't make any money by writing *Voices*, I like to think it helps, at least a few people. Wanting to help people has been one of my goals since I began using an Auto-Com and I feel this newsletter is letting me achieve this goal, at least somewhat. I have hope I will achieve my other goals. Therefore, I can't say my life is wonderful, but it certainly isn't awful either.

*To subscribe to Mary Ann's newsletter, write:*

Mary Ann Merchen  
723 Oak St. #115  
Danville, IL, 61832

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*I was thrilled when Alan sent his article to **Communicating Together**. It's always exciting to hear how AAC users from other countries function. He seems to have a positive attitude towards life. We are pleased to have his article.*

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## Life Through the Eyes of a Non-speaker

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ALAN MCGREGOR

My name is Alan McGregor and I am twenty-three years old. I live in Glamis, which is a small village in Scotland, with my parents and a twin brother as well as an older brother. I am a non-speaker through cerebral palsy.

Originally my parents were told by their doctor that my disabilities would not enable me to walk, but seeing two brothers running around I wanted to join them so I grew to be able to walk in my own way.

At the moment, I use a number of different ways to communicate. I do have a portable speaking machine, a

'Vois 135'. It can say words and short phrases. I got this when I was fifteen. It was a breakthrough but not good enough. The sound it produced was bad. At first it seemed good but then I felt disappointed in it. I also have a word card that has 400 words on it that I can point to. I use a few hand signs and say a few words.

With all these methods together I can communicate quite well. There can be problems with people not understanding how the methods work, though. Sometimes people actually pick up my word board and look at it with interest, and then ask me questions about it. They are still holding on to my word board. They are wanting me to speak but it is like they are holding on to my tongue!

Being a non-speaking person means that sometimes I feel sad. Because I have difficulty in communicating people tend not to speak to me. I think they are a bit afraid. They are afraid it will be too difficult to communicate with me. I don't think people mean to be bad. I try to put myself in their place. I can see how it would be difficult for me if I was in their position. I am always hoping that people will try to speak with me even though it's difficult. I

am also nervous about speaking with people, but I do try. When I'm with other people and they are all speaking away to each other and I am left out of it, I sometimes feel as if I must have two heads! It makes me feel quite lonely at times, even when I'm with other people.

I get angry sometimes, and frustrated, when the word I want to say is not on my word board, especially if people ask me questions which are difficult to answer with the word board. Yes or no questions sometimes help me to get across what I want. But don't be like the person who said to me: "Do you want a hot drink or a cold one? Yes or no!"

Having difficulties with reading has made it harder for me. I went to a special school which I feel did not stretch my abilities to their limits. When I was seven I started to learn to read and I have not stopped yet. I find reading very difficult. A complete pain! Only now I am beginning to feel that I am improving. At this present rate I should be a pretty good reader by the time I reach eighty. Just in time to read the words on my grave stone!

There is one thing I find which really helps me when I'm feeling bad. I find that music has a lot of power to



make me feel better. One of my interests is writing songs which I do with a computer and a key-board. I have written a number of songs. I have a friend who is a musician and who has a recording studio. He and I have produced two tapes of my music. The last tape we made had two songs that were sung by myself using the voice synthesizer.

At Dundee University I am helping to work on new ideas to assist non-speaking people to communicate using a voice synthesizer linked to a computer. With a system we have been developing I have been able to tell people about myself a bit better. The idea is to store lots of things a person would want to say in the future and to have a way to find these things easily when they are wanted. It is a very difficult problem, but we hope some of the ideas we are working on will help.

In the future I know that things are going to get better. Technology is on my side. Some people hope that in the future a computer system might be able to read your thoughts for you. I think this idea is really pie

in the sky. But if it could happen it would be a tremendous help to non-speakers.

It would be good if there was a machine that could be hand-held so I could have near normal speech always with me. What I would like to see would be a machine small enough to be strapped to the back of your arm, rather like a watch. It would also have some sort of speaking attachment. This would ideally be carried in the area of the shirt collar. This would make the speaking come from as near as possible to the throat. So it would imitate normal conversation better. The computer would have interchangeable discs, according to the conversation. And it might even be persuaded to print money as well!

Another one of my main interests is swimming. I take part regularly in swimming competitions for disabled people. I swim for the Scottish Team and have been to Belgium, Holland, the U.S. and Spain for international competitions. I train for about four hours each week unless there is a competition coming

up and then I add two more hours. It was a good year for me in 1992 with my swimming, as I was accepted to take part in the Paralympics in Barcelona. I won three bronze medals. I wrote a song about all of my feelings about being at the Paralympics. The song is called Magic of the Paralympics. I would like to be able to compete in the 1996 Games in the U.S.A. This will mean that I will have to keep the training up because no computer can do that for me.

In the future I want to have a job and live an ordinary life. As music is very important to me a job in that field would make me very happy. Just now I am involved with my swimming training, and composing music, and I am a voluntary helper with research at the University of Dundee. So I am always on the go.

In the future I hope to meet someone special who can share my interests and with whom I could settle down. These things take time and I am still young.

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*From the leading edge of the nonspeech communication movement*

## AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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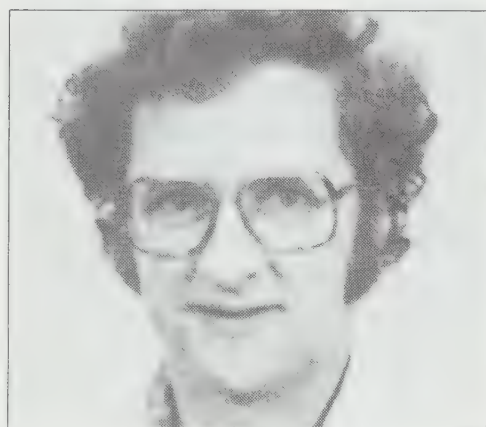
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## Thoughts on Michael Oliver's - The Politics of Disablement

GEB VERBURG



Writing for **Communicating Together** tends to get me in my "enfant terrible" mode. That is not to say that I am not terrible at other times but **Communicating Together** brings out my compulsion to criticize stronger than other media. For this issue, however, I'm stumped, I found someone, — not just someone, I found a whole journal — that is doing a much better job of criticizing. So much better that it has *me* on the defensive. The person I am referring to is Michael Oliver and his 1990 book "The Politics of Disablement" by MacMillan, London (ISBN # 0-333-43293-2 (paperback) or # 0-333-43292-4 (hard cover). The journal is: "Disability, Handicap & Society", the next (January 1994) issue of which will be called "Disability and Society". I can recommend both Oliver's book and the D&S journal for a sound, if somewhat left-wing, analysis of disability, or rather disablement issues.

I will not do an official book review of Oliver's book but all page references will be to Oliver (1990).

Other sources drawn from the book will not be re-referenced. I wanted to just excerpt the issues that I felt were particularly stinging, true and especially discomforting to me and I expect to you if you are an able-bodied professional or researcher. The adjective 'able-bodied' is important because, in my reading of Oliver and some of the other authors of the D&S, it confers doubt on my (our) qualification(s) to do the work we do.

Oliver's main points are that disability is created by society, or that disability is a mindset of the rest of society who see disabled persons as "tragic" and in need of "compensation" or charity. Such a mindset, when pervasive, has the effect of communicating to people with disabilities that they are tragic and less able than the average "normal" man, woman, and child. All of this sounds terrible and I will deny that I feel that way about the disabled people I know and, I believe, about all disabled persons. And yet, I also know that if I were given a choice between talking or AAC, wheeling or walking, to be able to see or not to see, I would choose to remain as I am now.

Oliver asserts that what is needed is a theory of disability. He proposes a radical change in outlook from one in which disability is perceived as a "personal tragedy" to one in which disability is defined as "social oppression". In the first case people with disabilities "will be treated as if they are victims of some tragic happening or circumstance" (p. 2); whereas in the second view "disabled people will be seen as the collective victims of an uncaring or unknowing society." The two views i.e. personal tragedy vs social oppression can be expected to lead to

very different treatments, attitudes and behaviours towards people with disabilities.

It is, I believe, for these reasons that Oliver is convinced that people with disabilities must develop an identity as "disabled persons"; to counteract society's (?unintended?) oppression. And although not intentionally setting out to bash clinicians, professionals, and researchers, Oliver's book upset me much more than Independence '92. Mostly because his analysis is so harshly true, so honest, and so seemingly, unalterably how-things-are: in spite of Employment Equity, in spite of ADA, in spite of Integration. We are still compensating, we still need charity, we still need special grants, special accommodations. We have not yet recreated the world to be accessible to all, and worst of all we have not recreated our minds to see and treat people with disabilities as equals.

Oliver draws a parallel with other liberation or rights movements e.g. blacks, women, gays such as the Black Power movement, with demonstrations, political protests, court and civil (disobedience) actions, and with slogans like "Black is Beautiful", that helped African-Americans to win basic rights and take pride in their heritage. And just as feminism has helped woman achieve greater equality, so Oliver believes that people who are disabled can (and will in due course) develop "personal and public identities" (p. 106) that are no longer dependent on the able-bodied majority's idea of what is normal, what is independent, integrated, employed.

The deaf community, or at least part of this community has developed the concept and attitudes of the "deaf culture" as an existence of a



deaf person that is sufficient in and of itself and not in need of medical or technological intervention to reach fulfillment as a person. Members of the deaf culture refuse to undergo medical treatment to restore their hearing. They might say with Oliver that we, hearing people, disable deaf people by our failure to learn how to communicate with them. For people who use AAC devices one could probably say the same and shunt more of the responsibility for not being able to communicate with nonspeaking persons onto the community or the AAC user's immediate environment.

## The Evidence

Let me communicate some of the things that made me uncomfortable, for example the kind of questions that I used to ask in surveys or interviews. I'll give you two examples of questions. We could ask a question like this: "How difficult is it for you to get about your immediate neighbourhood on your own?" (p. 7) implying that it is somehow a problem of the respondents that they cannot get about in their own neighbourhood. Or we could ask this same question like this: "What are the environmental constraints which make it difficult for you to get about in your immediate neighbourhood?" (p. 8). It is the same question but it has a totally different blame pattern and totally different a priori normality assumptions. Here is another one: "Does your health problem/disability prevent you from going out as often or as far as you would like?" (p. 7) and the same question now with the society focus: "Are there any transport or financial problems which prevent you from going out as often or as far as you would like?" (p. 8). As a researcher I have been asking my questions from the point of view of what is given (?normal?) to me. I never realized that by asking questions exclusively from the point of

view of the disabling condition as the cause of obstacles encountered I am in a way blaming the disabled person, I am judging them by my, that is able-bodied persons' standards. What gives me and other researchers (clinicians) the right to do so? Do we do it because we are in a majority? Or do we fail to think? Or do able-bodied researchers and clinicians ask our questions as we do because we "do not [our]selves experience the daily problems of disability" (Davis in Oliver p. 5).

I have much trouble with Oliver and others' assertion that professionals and/or researchers are working more for our career than for people with disabilities (pp. 9, 115). I am skeptical of statements that pit professionals against clients, such as "a professional/client relationship which enshrines the professional in a world of exclusive and privileged knowledge, and consequently entombs the individual with learning difficulties in a fundamental dependent role" (p. 90, from Brechin and Swain, 1988, p. 218). 'Enshrine' vs 'entombs' and 'exclusive and privileged' vs 'dependent', terms like these are chosen to dichotomize or politicize. Real life is not half as bad as all this. Professionals must have knowledge and skills, otherwise they would be useless or dangerous. There is nothing exclusive about that knowledge other than that it usually takes time for any person to acquire it through the educational process. That sounds too formal, I know that there has been jargon-use or shop-talk. The professionals I know have abandoned jargon a long time ago. And there is not a service in our Centre that is not actively educating parents and clients. So, the knowledge is not privileged anymore; it is just not so widespread that it is part of everybody's education. Maybe it should be and maybe it will be some day

but until then it will be good to have people who have specialized knowledge of disabilities.

One last comment on the presumed career hungry-ness of clinicians, professionals, engineers, researchers. Rachel Hirst, during a visit to Toronto where we discussed this issue, warned that professionals, engineers, and researchers have an option "They can pick up and leave the field at a moment's notice and apply their skills in a different field". Personally, I can add that it is not the salaries that are keeping the professionals in the field. For most of the "technie" persons it is the challenge offered by the work, as well as the evidence that many clients seek out our services, benefit from them, and are happy with the services and devices provided.

## Of or For the Critical Issue

The real hub of the advocacy, attitude, behaviour, service, rehabilitation issue is the legitimacy of doing things for (and to) people with disabilities. We do not organize telethons for cute little kids with red hair, or for kids with blonde hair and dimples in their chins. They don't need telethons. Why do children with disabilities need telethons? We do not prescribe tricycles for children with four working limbs and brown eyes. We do not need a doctor's permission (sorry, prescription) to buy a new car. In the world of disabled people, telethons are happening, unrelated adults make decisions about your (disabled) child. Grown-up people can be stalled in their request for a powered wheelchair by a well-meaning therapist who wants to prescribe headswitches that are ineffective and that look like a devil's horns. This is happening, today, it is personally degrading, it is wasteful, and counterproductive. All this because some-long-time in the past, society decided to make all disabilities a part of the medical system. Disabled people



became patients, hence incompetent, unable to make decisions, incapable of choosing for themselves. Time and bureaucracy did its work and people with disabilities or their families became less and less able to make their own decisions, hemmed in by policies, attitudes, and an unending stream of well-meaning professionals.

And now, as another mini-age of Enlightenment and Budget Cuts (The Nickel Age) sets in we have to get out of that ugly mistake again. First of all we will try and restore power to people with disabilities without reducing the power of the medical system (we always want to eat our cake and have it too). That won't do. The cuts have to come at the heart of the problem. But enough of this. Oliver's analysis does not go as far as this. He peters out into some wishful social change track, which, though full of hope and good feeling appears very vague and unsupported. His book remains a very solid analysis of the problems and as such a great starting point for straightening things out.

### What Can We Do?

Firstly, we can simply deny Oliver's analysis or any truth that might be hidden in his book. Or, we can say that Oliver is really a minority opinion, far to the left and therefore ignorable. We could even accuse him of being negative. According to several recent management rags, "negativity" has been identified as a distinct ailment of some members in each organization. And like the "bad apples" of yesterday "negative people" must be purged from an organization. We can simply decide collectively that Oliver is "negative" and every self-respecting manager will know what he (and an occasional she) must do about that.

I think it is not that easy. Yes, Oliver is rather left of centre, he is critical but I believe that he is

correct in his analysis. I don't think that he offers a cure or a solution but his criticism delivers insight and empowers.

As a possible second solution should we, professionals and researchers, just get out of rehabilitation and look for different jobs? What about the skills, what about the commitments that would be lost? I as a researcher have skills that can be applied anywhere else but very few people with disabilities have research and development skills. So what? What good has research done or is it doing? What about the development of rehabilitation technology? Will products still be developed? Which ones? Ones that are needed or only the ones that make a buck? My preference of course would be for some kind of partnership in which the skills of the professionals and R&D (research and development) people are linked with the experience and knowledge of people with disabilities. Together we could work on product development, and perhaps even attitude change or rather, no less than the change of society. I'm game; I never really left the barricades.

### A Hope

Finally, I had wanted to make the point that changes in attitudes or behaviour towards more positive attitudes or non-discriminatory or non-disabling attitudes are *not self-perpetuating*. They just die out unless one keeps on training. And that is of course entirely in agreement with Oliver's main points. As long as we see people with disabilities as victims of tragedy than we must see them as less able, pitiable, in need of compensation, less capable than the next able-bodied person. The perspective of disability as tragedy sustains an attitude of underestimation, of inequality. Until we acknowledge that and change the way we, as a society, look at people with disability we are all fighting an

uphill battle. Only when disabled people and able bodied people begin to look at themselves and each other as people with different skills, (sometimes) different bodies, but equal potential and equal but different abilities, only then may we begin to stop worrying about such issues as tragedy vs oppression, doing things for people with disabilities and disabled people controlling their lives.

I'm optimistic that we can learn to work together. It will not be easy but at least the economy is on our side. The bureaucratic systems always cost more than self-help or community activity. As long as enough people with disabilities gain positions of control, I believe that everyone can benefit; disabled persons, the medical / rehabilitation juggernaut and society at large.

### Reference

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### Notice to People in developing countries Working in AAC

As part of our commitment to support AAC in developing countries, we are pleased to offer back issues of **Communicating Together** to resource centres or other groups in developing countries. Please write to *Sharing to Learn* with your request indicating the issues you require. You need only arrange to pay shipping charges. Our supplies are limited but we will do our best to fill requests.



## Who Am I? Do I Dare to Go Where Eagles Go?

PAUL MARSHALL



Hi gang, it is time to read *Paul's Place!* Boy! I bet you can hardly wait. Well, the wait is over. The dawning of a new article has begun. Paul has been busy at his keyboard trying to come up with an article that deals with being "handicapped" in a "normal" world.

Let's dive in, shall we? In this article I want to address the dare, the fear, the flight and the soaring of being an AAC user in the hopes you will start to soar above the views that some people may hold onto. Let's take our flight and only look back to see how far we have come. Come, let's dare to be us.

### The Dare

Living with any "handicap" is daring. We have two options; the first choice that we have is to be viewed as a "handicapped person". The second is to be viewed as a "person" with a handicap. Let's not kid ourselves, it is very important how we view ourselves. The quality of life depends largely on how we see and react to things. The dare is set in front of us. The dare of taking up our life and running with it, making today the best day of our lives. Or the dare of letting life rule us. Life is waiting for you and me to make our move.

### Dare I Go Where Eagles Go?

*Do I dare to soar where no man  
has gone?  
Do I dare to soar above where only  
eagles soar?  
Am I that fearless?*

*Yes I will take up my flight.  
I will dare to be me with my life.  
I will soar  
and above the clouds I will go.  
Away, Away I must go.*

*Handicapped or not, here I am  
Free to be the individual I was  
called to be.  
Look at me, ready to take my wings.  
Here I am, gone I will be.  
Here to serve, in a moment  
my name will fade away.*

**Paul Marshall**

It is like trying to walk a tight rope when you have C.P.. It can't be done but it doesn't mean you stop trying to do everything. So you can't walk a tight rope. You try and you master whatever you can. When I was my in teens, I wanted a "safe" life. I soon realized to live a "safe life" was an improbability for me because I wanted to live life and I hoped to make a difference. So I quickly changed my outlook, in order to develop into a person who was willing to go for it all. By not taking dares or not taking chances, we have a chance of becoming tired and resentful with life. Whether we are "handicapped" or so called

"normal" we must realize that life has many challenges and it is up to the individual to meet those challenges in a way they can grow and benefit from.

I believe deeply there are many levels of life we can choose. What each of us as an individual has to acknowledge and grasp is the level of life that we want to lead. Life is made up of black and white issues. You either adapt to your environment or you make war with it. Adapting to your world is not giving up and letting your world tell you what to do and how to do it. Adapting to your circumstance is having peace and contentment. Change



must take place. On the other hand, if we make war against what is happening around us, then we are open to more discontent and change might be harder to gain.

Do we dare to soar above the materialistic side of life? Are we willing to lead a life of “self-power” that is a model for others to follow? Are we ready to dare to go above the trappings and the mind sets of being a “handicapped” person?

### The Fear

Fear is a powerful thing. Fear is the driving force that holds us back from doing things. It can also *make* us do things. After all, society itself is made up of fear. Fear of job loss, fear of not having the money to live etc. Fear can overrule if we let it. If we want to master living with a “handicap”, then we have to learn how to deal with fear. To me, it is all in the doing — feeling self-worth and feeling good about myself. It is not about letting the outer events of our life that moves the gauge of happiness, but it is about our “inward gauge” that needs to move us on. I can remember the first time I went for a walk on a creek covered over

with thick ice. The fear of falling was real, but the joy I got from seeing the bank and the trees covered with snow was well worth that fear. When I was on the bank, I looked back and said “There! I did it and I will do it again.” I was not out to prove it to anyone but myself. My “inward gauge” moved.

I am past the stage of trying to prove myself to the world or of being fearful of not fitting in. The funny thing is, the less I try to fit in, the easier it becomes to fit in society and to demonstrate that I also have something to offer. If I want to make a contribution with my life, then I learn to throw off the pain that people often give without really knowing it. In life there are two ways to look at the world: a) Because life treated me badly, I in turn will treat the world badly and take out my anger and my hostility on the world. b) Because the world or life treated me badly I will in turn rise above and learn how to live a life without anger and hostility. This in my mind is going where only eagles go because very few of us really know how to soar above the materialism of this world.

### The Flight and the Soaring of Being an AAC User.

I know the painful hurts of being “handicapped”. Sometimes the hurts really get to you. I find the more I am at peace with who I am, the easier it becomes to deal with each circumstance I come in contact with. Sometimes we might feel that if only we could change the world, things would be better. A lot of times it is for us to change and not our circumstances. By changing our views of what is going on around us, we may find the freedom to be us. Contentment is a powerful tool. In being content we can react with a mind that isn’t trying to fight but with a mind that is ready to take action. By being at peace with who we are, we can get in touch with our own thoughts and feelings. When we are content, things start happening. Change comes about when we know who we are as an individual.

This is what I call going where only eagles go. It doesn’t take a special kind of person to live above the trials that hold us back. It only takes a person that sees the beauty of each day.

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### Recommended Reading

For all those who have been following the debate regarding Facilitated Communication, we highly recommend reading Rosemary Crossley’s new book entitled, *Facilitated Communication Training*. The cover aptly portrays what Crossley urges should be the ultimate aim for all users of Facilitated Communication — a withdrawal of the facilitator’s physical contact and the individual gaining greater independence. In attempting to evaluate Facilitated Communication practices as implemented today, it is helpful to return to the originator of the approach and consider what she believes are the critical features of this training method. The book is published by Teachers College press, Teachers College, Columbia University, New York, 1994. The 150 pages include Crossley’s perspectives on such topics as assessment, how-to’s, literacy, independence and word-finding problems. As well there are two case studies and a glossary of terms. As we view the various North American media presentations — both pro and con Facilitated Communication — and learn of the legal proceedings arising from the Facilitated Communication programs, it would seem prudent to return to the source. How many of the current problems arise from the method? How many arise from the implementation?



## Augmentative Communication and Empowerment Supports

DIANE BRYEN, KIRK BEHNKE,  
TERESA McKEE

*We wish to thank Diane Bryen, Kirk Behnke and Teresa McKee for sending us this information regarding ACES and the ACES Summer Institute. As we consider how persons who use AAC feel about themselves, it is interesting to learn about an empowerment course with the many dimensions of the Temple University program.*

In order to enhance the communication effectiveness of adults with significant physical and speech disabilities, *Augmentative Communication and Empowerment Supports (ACES)* was established in 1988 at Temple University. The purpose of ACES is to assist individuals with significant physical and speech disabilities to develop a literal, social and political voice in order to remove the perceived "cloak of incompetence" experienced by many people with significant disabilities, to enhance opportunities to live independently and to gain access to further education and employment. This is done by:

1. Providing needed augmentative communication technology and "user friendly" immersion training and ongoing supports in the use and mastery of augmentative communication and related assistive technologies.
2. Preventing, reducing or eliminating depression and learned

helplessness by acquiring the needed knowledge and skills to become more assertive and self-directing in their lives.

3. Providing the needed knowledge and skills for understanding and asserting their basic civil rights under federal statutes such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.
4. Increasing their independent living, educational and employment prospects by providing communication devices, training and ongoing support in such areas as:
  - methods for obtaining, using, customizing, adapting and maintaining communication devices and related assistive technologies;
  - using communication technology to increase personal choice and control in their own lives;
  - managing and integrating the use of communication technology into their daily lives; and
  - using augmentative communication and related technologies to enhance educational and employment skills.

In addition, a major purpose of ACES is to train professionals, tutors and allies to be partners and advocates in providing needed assistive technology, services and supports to individuals with significant physical and speech disabilities.

Central to ACES is the *Summer Institute* -- a two-week "immersion" training program and year-long

follow-up for ten to twelve individuals with significant physical and speech disabilities. During the ACES Summer Institute, sixty hours of intensive instruction in the use of advanced, portable communication devices with voice output is provided. Participants are immersed in the use of their communication device in a learning community that supports and encourages the use of their "new voices" during the entire day. In addition, participants have access to competent AAC role models. Participants are introduced to word processing by interfacing their communication devices with generic computers.

An empowerment course is also provided by people with disabilities. The purpose of the empowerment course is two-fold. First, once students begin to learn to use their new "voices" in a more literal and social sense (e.g., face-to-face communication), there is a need to learn to use their new voices in a political sense (e.g., to obtain employment or continued education, housing, and barrier-free transportation; to manage their personal assistants). Second, the empowerment course offers opportunities whereby their communication devices and word processing skills can be integrated into an educational setting where notes are taken, discussions are held, and homework is completed.

Use of Temple University's campus housing, recreational, cultural, and computer facilities are provided during ACES Summer Institute as are personal assistance services for those participants who require them. A host-mentor program links people with disabilities who are living and working in Philadelphia with ACES partici-



pants. The host-mentor program not only provides role models for participants, but it provides additional social, recreational, and cultural opportunities for them. Finally, for the entire twelve-day Institute, each participant has a tutor and the use of a custom designed communication device for training. All communication equipment is rented for the two week Institute and for a six-week follow-up period until permanent funding is secured. Prior to the ACES' Summer Institute, evaluations of each participant are conducted to determine whether the individual is an appropriate candidate for an advanced communication device and for the Institute, and to ascertain which communication device appears to be the most appropriate one for him/her. Follow-up technical assistance, ongoing training, and supports to each participant are provided for one year. More than fifty people with significant speech disabilities have benefited from ACES' Summer Institute during the past six years.

In addition, training is provided to graduate students, professionals and community-based tutors so they can continue instruction and support of participants after the conclusion of the Summer Institute and to provide advocacy for and training to others. Approximately sixty professionals and allies have been trained. They came from eight states (Pennsylvania, New Jersey, Ohio, Mississippi, Massachusetts, Michigan, New York, and Indiana) and three foreign countries (Argentina, Israel and Germany) and have had an impact on thousands of children and adults with significant speech disabilities.

Finally as part of the Summer Institute, follow-up training and support, coordination, and technical assistance for one year is provided to all participants of ACES' Institute. Like learning a second language, mastering the use of an AAC device

and related assistive technologies takes considerable training. Although sixty hours of intensive instruction is provided during the Summer Institute, experience suggests that it takes most individuals 100 to 200 hours of additional instruction to master the "language" of the equipment's software, to master its full system operation, to learn how to customize it for current and future educational or vocational needs, to integrate its use into daily life, and to learn how to maintain the equipment — in other words to become a competent communicator.

Better than a description is the reaction of some of the participants.

To my new friends, I have this piece of advice and it is to use your Liberators™ to express your ideas, desires, and all the things that you want to do. Ask a lot of questions too. If people don't listen to you, try again.

I would like to share some thoughts with my new friends and co-students - Carrie Bona, Demetric Cotton, Jodi-Lynn Hamilton, Linda Owens, Shelly Tannenbaum, Susan Williams, and Connie Wyeth. Today is your day. Keep using your new voices! To Carrie, Shelly, Linda and Connie, keep practicing because you will be able to learn how to use it. To Demetric, go back south to Mississippi and achieve your goal of becoming a computer programmer. I would like to tell Jodi-Lynn to learn to use your Liberator to tell your message, because the people around you want to know what you have to say. To Susan, use your Liberator™ as a warning tool so you can go anywhere in your electric wheelchair.

*Paul Garrick*

Hello, my name is John Stuart Povall. I am from Cleveland, Mississippi, where I am a senior at Delta State University majoring in Computer Information Systems.

When I started the first grade in 1976, I was one of the first children with a disability to be allowed to attend regular schools. Being one of the first meant I had to break down all of the barriers. The biggest barrier was opening my teachers' minds to the fact I could learn like anyone else. My

parents led the battle to break that barrier which was broken down to some degree when I was given the opportunity to take the test for the gifted program and passed. However, this barrier wasn't broken down completely because of my communication difficulties. But now with the introduction to my TouchTalker™ I am able to communicate more effectively because it lets me participate in classroom discussions, conversations with groups and on the telephone with friends.

I am thankful for the opportunity to attend the Summer Institute and would like to thank all those who made it possible. The Summer Institute has taught me to use my TouchTalker™ with Word Strategy to express my thoughts and opinions more quickly. The empowerment course has opened my eyes to the needs of other people with disabilities as well as giving me information on programs that will be helpful to me.

I will have a lot of work to do when I get back to Mississippi, so I will see ya'll later.

*John Stuart Povall*

#### **Note:**

There were several other testimonials that because of space limitations could not be included. If the reader is interested in them, please write ACES.

The Seventh Annual ACES Institute will be held from July 31 through August 12, 1994. For more information about ACES, contact either Dr. Diane N. Bryen or Kirk Behnke at the Institute on Disabilities/UAP, 423 Ritter Hall Annex, Temple University, Philadelphia, PA 19122; 1-800 204 - PIAT.

#### **Join ISAAC Now**

The International Society for Augmentative and Alternative Communication (ISAAC) offers members reduced rates for: **Communicating Together**, **Communication Outlook**, and **Augmentative and Alternative Communication** (AAC journal).

For a membership application or other information about ISAAC, write: ISAAC, P.O. Box 1762, Station R, Toronto, Ontario, Canada, M4G 4A3.







### Translations in Minsymbol/Words Strategy icon labels and Blissymbols

(Waving the snake at his partner.)

It's not a real snake.

I'm 'tending this is a snake.  
(Stops moving it and looks at the  
snake.) By the way, it is a snake.

'Tend he'll bite me. (Turns the snake's head towards himself.)  
I said, 'No.' (Speaking to the snake.)

(Moves the snake towards the back of the large wooden car.)  
'Tend it bited your licence plate.  
'Tend it was just a little crack.

It's not a  
real  
snake.

I'm 'tending  
this  
is a snake.  
By the way, it is a snake.

'Tend he'll bite me.  
I said, "No."

'Tend it  
bited  
your  
licence plate.

'Tend it  
was just a  
little  
crack.

It • knot • bee • a  
• money + adjective  
• elephants + snail  
|  $\hat{\Phi}$  - | \  $\check{\Phi}$  ~

I • bee • god + knot + money  
• remember + demonstrative  
verb + s • a • elephants + snail

$$1, \hat{u}, \hat{\theta}, \omega$$
$$\underline{\hat{a}}_{\lambda_3} \nabla \perp_1, \perp_1 \circ, -11.$$

god + knot + money • it + end  
apple + dog + verb (ed)  
• you + possessive  
• van + dog

$$\hat{\mathbb{E}}_1 \nabla \perp_{2+} \square \# \textcircled{\text{a}}$$

- god + knot + money • it + end
- verb(ed) • scales + adverb • a
- dice + adjective
- hammer + over (cup)

① ② ③ ④

Garvey, 1984, p. 9.

Original children's conversation  
reprinted by permission  
of the publishers  
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by Catherine Garvey,  
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Harvard University Pres.  
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I appreciate Kari and Jason demonstrating that the above vocabulary items can be generated through Blissymbolics and Words Strategy/Minsymbols. If other graphic systems/sets can be used to produce these four-year-old utterances, the invitation to send the translations to **Communicating Together** stands!

Even after we identify the currently available graphic strategies for representing the vocabulary items required by speaking preschoolers, however, the much greater challenge remains — analysing the cognitive and literacy skills required by the current alternatives, considering which of these skills are attainable by pre-schoolers, and discovering and creating new symbols which are appropriate for two, three, four and five-year-olds. In the toddler/ pre-school period of rapid development, we must remain open to the need for more than one system (McNaughton, 1993). We must seriously consider what can be achieved by the young child as he or she develops and how we can facilitate the building of new learnings on old.

The differences between young children using speech and using an aided communication system is awesome! We need to understand what is involved in learning the symbols which represent concepts regularly used in young children's utterances, and in displaying and retrieving the number of symbols required. As well, we must find ways for young children to construct new words for items not included on the manual board, computer or communication device.

I know there are many parents, teachers and clinicians who are adapting and innovating in a variety of ways to give the preschool child who is nonspeaking as many opportunities to communicate as our current knowledge allows. I also know there are many who are providing ready-made words and phrases over which the child has little control. The child's choice becomes whether to use or not use what is available, not whether to *select* or *create* the appropriate word or phrase. For parents of children like Adam Gregory, there is the option of encouraging gestures and body language. For parents of

children with severe physical limitations, however, the options for initiations are very limited.

Many questions regarding language development have been raised and discussed in *SymbolTalk* over the past several years. The objective seems clear: a graphic system which empowers the young child — providing the opportunity to independently select, retrieve, generate/construct the symbols representing the concepts which are taken for granted by speaking children. Is it possible? How close can we come to the ideal? How can we ensure that what is “said” by nonspeaking two, three, four and five-year-olds is what they intend and “understand” not what the adult has planned, programmed and allowed them to say? We are forever reminded that there is much to learn and no time for complacency! Please send your thoughts to *SymbolTalk*.

## Reference

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